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The grace of motherhood: disabled women contending with societal denial of intimacy, pregnancy, and motherhood in Ethiopia

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ABSTRACT

This study aimed to provide better understanding of intimacy and marriage, pregnancy, birth, and motherhood experiences of women with disability in Ethiopia. Qualitative, in-depth, and semi-structured interviews along with personal observations were used to explore the full experiences of participants, as told in their own words. The result of the interviews indicated that relationships and motherhood proved a very rewarding option for women with disabilities. They also expressed their need for intimacy regardless of society's denial. Challenges identified include negative societal attitudes toward women with disabilities regarding relationship, pregnancy, and child-rearing. Accessibility of health centers in addition to the ignorance and negative attitudes of the physicians are also reported to be major challenges for the interviewees. This study highlights how rewarding the experience of motherhood was for the interviewees and also shows that women with disabilities face challenges at every step of their experiences, because of society's prejudices toward disability.

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Motherhood; intimacy;
pregnancy; disabled women;
Ethiopia

Points of Interest

- This paper reports on Ethiopian disabled women's experience on intimacy, pregnancy and motherhood.
- Interview data revealed that mothers experienced significant challenges with regard to accessibility of health centers, physician's lack of knowledge

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about and problematic attitudes toward them and more general societal prejudices towards individuals with disability.

- The interview data showed that the experience of intimacy and be(com)ing empowered women.

Introduction

The desire to have children has customarily been elucidated by the existence of ‘the maternal drive’: motherhood is often reflected as a typical part of every woman’s female identity (Haelyon 2006; Mcquillan et al. 2008). Furthermore, one of the major social roles expected from women is motherhood (Poole et al. 2013). Although this expectation is a worldwide injunctive for women (Kallianes and Rubenfeld 1997), in the modern western world motherhood has become more ‘optional’ (Thomas 1997; Prilleltensky 2003). In the culture of developing countries, motherhood is not viewed as optional; rather, society strongly expects women to marry and have children.

However, the majority of disabled women globally are denied the possibility of intimacy or marriage (Frohman and Ortoleva 2013) and are commonly perceived as asexual (Price 2011; Wickenden et al. 2013; Malacrida 2015). Most people in developing countries tend to believe that disabled women cannot be involved in relationships and have children. Women with disabilities in developing countries are particularly vulnerable to socially constructed misconceptions (Anastasiou and Kauffman 2011) regarding the impossibility and/or inability of being involved in relationships and experiencing pregnancy and motherhood. In some cases women with disabilities may get pregnant due to sexual abuse (Kvam and Braathen 2008). Sexual violence is a profound human rights violation and public health concern (Dartnall and Jewkes 2013). Nevertheless, women with disability who do become mothers often experience motherhood as a blessing. This is to some extent also true for women who became pregnant as a consequence of sexual abuse (Malacrida 2009).

Furthermore, disabled mothers are often viewed as incapable of handling a maternal role; they are in many ways denied children and derided as mothers (Kocher 1994; Price 2011). Thus, many disabled women are considered as being unable to live up to traditional role expectations for women in society. They are less likely to get married than other women (Groce 2004), highly vulnerable to divorce, and frequently raise children as single mothers (Kassah, Kassah, and Agbota 2014). During pregnancy, women in developing countries experience negative attitudes and behavior from society (Prilleltensky 2003) and from professional caregivers (Smith et al. 2004; Bremer, Cockburn, and Ruth 2010; Walsh et al. 2011). Accessibility of the health centers is also a challenge for pregnant disabled women (Smith et al. 2004).

Yet in a previous interview study on educational and employment opportunities of disabled working women in Addis Ababa (Tefera and Van Engen 2016) we were struck by the empowerment that mothers exhibited as they talked about motherhood in the interviews. Although in a society such as Ethiopia becoming a mother when being disabled is considered hardly conceivable, most of our interviewees actually were mothers, and very proud of it too. The grace that motherhood gave our interviewees instigated us to delve deeper and go back to our interviewees and conduct additional interviews to probe more into their experiences of intimacy and marriage, pregnancy and giving birth, and their experiences of motherhood.

Objective of the study

Most of the developing countries' literature on disability has focused on social, economic, and health problems. This article aims to show the experiences of women with disabilities by focusing on their need for intimacy and marriage, how they enjoy their pregnancy period while also facing challenges, and how they manage their motherhood responsibilities and take pride in them. We analyze how social roles and expectations present additional challenges. Moreover, the article identifies and documents experiences of intimacy and marriage, pregnancy and giving birth, and motherhood experiences of women with disabilities in Ethiopia. We first describe our grounded methodological approach, our sampling procedure, the context of the study, and the steps of our data analysis. Then we present our findings thematically. We first discuss how societal expectations can disrupt experiences of intimacy and marriage life, then we discuss the different challenges faced during pregnancy and giving birth, and finally we discuss the many facets of motherhood experiences, both in how motherhood aggravates challenges and at the same time empowers and prides women with disabilities. In the discussion we reflect on our findings from a capability approach (Nussbaum 2006; Robeyns 2005; Sen 1999), a (family) quality of life approach (Brown and Faragher 2014), and a disability culture perspective (Kirsbaum 2000; Peters 2000; Koppers 2011; Ripat and Woodgate 2011).

Methodology

The approach used was purely inductive (Knox et al. 2000). In our previous study focusing on the opportunities and challenges women with disabilities had due to their disability in relation to education and employment (Tefera and van Engen 2016), those who were mothers strongly and repeatedly discussed the empowerment they gained through their motherhood experience. Their stories revealed that becoming involved in an intimate relationship and/or marriage is not a matter of due course and neither is pregnancy, giving birth, and motherhood. These themes were intertwined, and thus in our second study we probed more on these three aspects of disabled women's experiences. While selecting additional interviewees

other than those who were involved in the previous interviews, we preferred to again choose employed mothers with disabilities for consistency. Education and employment offer women opportunities to pursue capabilities that they value in life, and, as we found in our previous article, these capabilities are opportunities to pursue happiness in marriage and satisfaction with their role as mothers.

As an analytic approach we used qualitative methods that relied on data obtained from face-to-face interviews. The primary instruments were in-depth, semi-structured interviews and personal observations, which allowed exploration of the full experiences of participants' own points of view as told in their own words.

The 13 participants were employed women with physical or visual disabilities, and the interviewees were from the Addis Ababa metropolitan area, Ethiopia. The women experienced different types of disability; some were blind, or partially blind, and some of them had leg impairments. Leg impairment is generalized in this way because some interviewees were not sure about the type of their disability except that they have some kind of leg impairment. Of the interviewees with leg impairment, one uses a wheelchair and the others use crutches. Disability may be caused by many factors, such as birth defects, malnutrition, diseases, or inadequate medical care.

Snowball sampling (Sheu et al. 2007) was used to select employed disabled women. Interviews were conducted by the first author and took place at a site of the participant's choice. Five of the interviewees were interviewed twice. These women were interviewed for a longer time for the article on educational and employment opportunities (Tefera and Van Engen 2016) and interviewed for a shorter interview on their motherhood experiences a second time. Eight other interviewees were interviewed specifically for this study.

In general, interviews took approximately 30 minutes to one hour, with an average duration of about 45 minutes. The interviews were performed in Amharic (the native language of both the interviewer and interviewees). The interviews were audio-taped for later transcription, translation, and analysis. At the conclusion of the interview, field notes were completed by the interviewer (first author) on the interview location, length of the interview, perceptions of rapport, and other interview characteristics (e.g. interruptions). The field notes were used in interpreting transcripts as well as during data analysis to assess the trustworthiness and legitimacy of the narrative data.

Context of the study

Ethiopia is Africa's second most populated country, with 85 million people (Aguilar et al. 2014). Although it is difficult to obtain an accurate figure for disabled people in developing countries (Eide and Loeb 2005), five million people are reported to live with a disability in Ethiopia (Groce et al. 2013). The health services coverage in Ethiopia is one of the lowest in the world. The potential health services coverage, for instance, was limited to 51.2% of the population in 2000/01 (Demeke

et al. 2003). The coverage is biased toward urban areas and features low service coverage for women (Woldemicael and Tenkorang 2010). Moreover, an increasing number of medical doctors from Ethiopia work abroad because of the high level of remuneration they get in the western countries. For example, there are more Ethiopian medical doctors in Chicago than in Ethiopia (Itansa 2016).

Data analysis

The analytical approach is consistent with procedures established by Burnard (1991) (Lavelle and Dowling 2011; Tefera and Van Engen 2016). Burnard (1991) proposed a 14-stage method for semi-structured open-ended interviews but also suggested that the method could be modified when 'more clearly structured interviews' are used, as is applicable in this study, similar to those used by Lavelle and Dowling (2011) and Tefera and van Engen (2016).

In this study, interviews were recorded and then transcribed verbatim and translated from Amharic to English. The first stage involved taking notes after each interview and using them as 'memory joggers' during the initial analysis phase. The next stage involved reading through all of the transcribed interviews while making notes on the descriptions given. The following stage was focused on open coding and involved re-reading the transcripts. All four authors examined four or five interview transcripts each (together all 13 interviews) and identified themes and a category system. The transcripts were then examined again in the light of the themes generated by the first author and two trained colleagues, and themes were distinguished in the text using a color-coded system.

The text from the transcripts was then reorganized under the themes with attention to context maintained by working alongside complete copies of each transcript. These were then compared to the themes and categories identified in the analysis. All of the sections were filed together for direct reference when writing up the findings.

Findings

In the following excerpt the interviewee describes a discussion between her and a man who gave her a car ride, capturing the beliefs in society about the intimate lives of disabled women:

He asked, 'Is he your husband?' I said yes. 'How did he marry you?' 'Why wouldn't he marry me? I have also married him,' I said. This created a lot of questions in him. He was even driving at a very slow speed to continue the conversation. He said it is very astonishing. I said, 'Why? I am actually the one who needs to be admired.' He said that what he meant was the fact that he married me. I said, 'I have also married him,' and I was laughing a lot because the man was very astonished by this. He then said, 'OK, let me ask you one question: How can you sleep together?' I said, 'If it surprises you, I have two children.' He said, 'You were pregnant?' 'Yes,' I said. 'How did you get pregnant?' Again I said, 'Is it with my legs that I get pregnant? What is wrong with you?' He was very astonished, and

he said, 'Tell your husband that I admire him very much' He was very amazed; his admiration was for my husband. (Interviewee K)

This excerpt captures how a married mother of two children displays the societal perceptions about intimacy and marriage, pregnancy and childbirth, and motherhood for women with disabilities.

In this article we concentrate on three major themes: intimacy and marriage, pregnancy and childbirth, and motherhood. These themes are explored based on their association with and contradiction of society's perception, and they are illustrated by selecting expressive excerpts from the interviews with employed disabled mothers from Addis Ababa, Ethiopia. The first part of the presentation of the analysis deals with the intimacy and marriage experiences of the disabled women. The second part of the presentation of the analysis covers the experiences of pregnancy and childbirth of the disabled mothers. The last part of the presentation of the analysis looks at the motherhood experiences of disabled mothers, with four sub-themes: motherhood feelings, mother-child relationship, motherhood responsibilities, and social support and perception.

Intimacy and marriage

According to the interviewees, being involved in a relationship is very difficult for disabled women. If they are in a relationship, the relationship may not continue, as mentioned by the majority of the interviewees. Four major reasons were noted for separation from the fathers of their children. There are also some who stay in married life, which is discussed in the section on the experiences of the married disabled mothers. The four major reasons for being single disabled mothers include eschewal by non-disabled men, financial problems, interference by siblings, and refraining by the disabled woman herself.

Avoidance of men

From the interview results, a clear notion emerged that the interviewees consider that non-disabled men do not want to involve themselves in a relationship with a disabled woman even if they are attracted to her. This concept is shown clearly in the following excerpt:

There was one visually impaired, very attractive girl. She always dressed well and kept herself looking nice. Once she was in a taxi wearing eyeglasses and there was a man next to her. He wanted to introduce himself to her and they exchanged telephone numbers. Finally, she reached her destination. While she was going out of the taxi, he realized that she was blind, and he said to her 'Sorry! I don't want your number; do not try to call me.' (Interviewee G)

This quotation explains, on the one hand, the interest of the disabled woman in having a romantic relationship, and on the other the avoidance of the man from getting involved in a romantic relationship with the disabled woman. It also implies

the difficulty of intimacy and relationships with non-disabled men for disabled women.

Financial problems

On the contrary, the disabled women may establish a romantic relationship but then the relationship may not continue due to different reasons. Interviewee I explained this issue as follows:

[I]t was very difficult to convince my boyfriend about the issue because he was not interested in having a baby at that time due to our financial condition, which was [insufficient] to cover the expenses of a new child. But I was looking forward to have my baby. In fact, he asked me to get an abortion but I said no to him. As a spiritual person, nothing comes to you without God's will. It was what I was seeking for years I was longing to be a mother, to have my own baby. As a result of my refusal, we got separated.

In this situation, the relationship could not continue because of pregnancy. The boyfriend gave her an ultimatum to choose either the relationship or the child. The reason for asking for an abortion was the financial inability to support the coming child, which resulted in their separation.

Interference of siblings

Another reason for separation, stated by another interviewee, is the interference of siblings on both sides:

No, we did not continue to marriage. It was my own brother who tore us apart and separated us, and that was it There were no such things on his side. He even wanted to introduce me to his family. He wanted to marry and live with me There are also those in his family who think like my family, but he was not like that. I used to belittle myself, but he did not do that. (Interviewee E)

The interviewee here implies that the relationship was discontinued because of the intervention of the family. In Ethiopian culture, family life is extended (Hogan et al. 1999; Groce et al. 2013), and major decisions in life like marriage are mostly decided not only by the couple but also by the family members. When it comes to disabled women, such a culture is typically more severe. The reason for family involvement is mostly either protection or stigmatization, as was mentioned by the interviewees. That is, the family may become the major decision-maker on the marriage decision of their disabled daughter. They usually forbid their daughter with a disability from marriage for the reason of fear that she may be mistreated by a husband. Also, the family may share the belief of society that disability prevents their daughter with a disability from handling the required responsibilities of a wife in the Ethiopian context, such as handling household chores.

Avoidance of disabled women

The following excerpt entails the discontinuation of a relationship due to the decision of the disabled woman. Interviewee L mentioned her motivation to separate from her boyfriend as follows:

I had a boyfriend; actually, in our country it is not a simple matter for a physically disabled young female to have a boyfriend. There are a lot of problems. People shun you in a manner that is clearly observable or secretly based on reasons when you enter in such kind of relationships. ... I did not think about marriage; it was not in my dreams. I knew that it was possible but what I thought of first was the things which could obstruct it, so I did not give much thought to marriage. But when I say marriage, it is not only about the person who you marry; it is also the community that is there because of the relationship and being able to withstand the battle. This is, by the way, what I used to say at the time. I saw it as an unnecessary war; I saw it as an unnecessary sacrifice. So I blocked myself from getting into that situation, or I can say that I closed the opportunities that were leading to that because of fearing the results that would come afterwards, so as not to get hurt and make the sacrifice.

In this quotation the interviewee describes the case of separation from a boyfriend because of the disabled woman's choice. It tells how the fear of making an unnecessary sacrifice leads her to bring the relationship to an end. She reveals that the trepidation was related both to the person she would marry and to society's denial.

Marriage life

The second part of intimacy and marriage discusses the interviewees who are in married life. Married life for Ethiopian women is indispensable as within Ethiopian society people are likely to see a single woman as less fortunate, less respected, and less valued. Thus, families often push their daughters to marry as soon as possible. For women with disabilities, however, people in Ethiopian society expect the reverse and may react with disbelief if women with disability get married.

One interviewee who is married to a man with a disability stated:

... all the burdens are on me. Since he is unemployed at this moment, all the burdens are on me. In addition to that, he is not willing to help me at least by taking her [their daughter] to school. It is not difficult to take her to school because the school is not far from our house. As I have to prepare her lunch and make her ready, he should have at least taken her to school. Anyway, I am the one who takes my daughter to school, and after that I have to run to my office. (Interviewee A)

The interviewee here does not consider her husband as a helpful person, while another interviewee who married a non-disabled person is very happy with her husband's behavior:

Generally, if you are a physically disabled person there are many sacrifices you should make. But, as a matter of chance I have never faced all these difficulties in relation with my husband, his family members ... all of them are still good to me. (Interviewee G)

These two excerpts indicate the possibility of good married life with a non-disabled man and the likelihood of a less supportive married life by marrying a disabled man. Another interviewee mentioned that she divorced because of the behavioral change of her husband after having three children:

Gradually he started showing a new character that he did not have before. He backslid from faith, he became a drunk, and it was very, very difficult for me to live with him. I tried to help him to restore his faith, but he was not willing to accept my advice; instead, he refused to accept it. Finally, I took the issue to court to get my divorce paper so as to

keep my children with me to save them from his bad behavior. Finally, I got divorced and our relationship ended there. (Interviewee F)

The interviewee further explains that all the responsibilities of raising the three children are left to her, and she also mentions that she enjoys taking care of the children.

Generally, intimacy and married life are mostly difficult, as mentioned by most of the interviewees. Most of the difficulties are intertwined with negative attitudes toward disabled people. Most relationships did not last for long. Next to the romantic relationship, the significant theme identified was the pregnancy experiences of the interviewed disabled women.

Pregnancy and giving birth

The Ethiopian custom forbids having sex and children outside marriage; it is a taboo. This taboo is recognized for women with disabilities, as people cannot believe that men want intimacy with and to marry women with disabilities. Yet most of the mothers we interviewed were single mothers. The interview results show that all of the single mothers got pregnant unintentionally, yet all of them were happy after having children. One of the single mothers got pregnant twice as a consequence of rapes by different men from her neighborhood as she was staying in the house alone. Subsequently, this section discusses the attitudes and behaviors of physicians toward the pregnancy of disabled women and the accessibility of health centers for pregnant disabled women. From the seven interviewed single mothers, all but two of the fathers were denying their fatherhood and were not providing support at all. The other six interviewees got pregnant within marriage.

Undesired pregnancy

The time of pregnancy of the interviewees was difficult for different reasons. Some were hiding their pregnancies, as the following excerpt illustrates:

During pregnancy I did not go out for the whole nine months. When I was having the second baby I was even afraid to see people, as they were saying, 'How could she make the same mistake knowingly,' but I was raped for the second time. (Interviewee D)

This excerpt shows that the interviewee faced unwanted pregnancy and at the same time she was condemned by society. Rather than concentrating on the rape case it appears that society criticizes the disabled woman who was the victim. This made the time of pregnancy more difficult, since the interviewee stayed in her house for the whole nine months of her pregnancy. Another interviewee also revealed that she was hiding herself from people, including her family, until they started noticing her pregnancy:

I used to hide myself from my friends up until eight months. I even used to hide myself from my family members until they recognized it. After they learned it they accepted

my pregnancy. They were saying, 'Let her give birth because she is disabled; she will give birth to one who will lead her; her baby will have some benefit to her life.' (Interviewee C)

The following quotation illustrates that societal condemnation makes the pregnancy more uncomfortable in addition to the inconvenience of the disability:

A pregnant physically disabled person is seen as something weird. It is something outside the box, which they have not seen before. They think that 'She is walking with a crutch or she cannot walk on her legs well, but she is pregnant.' Other times also they see you as a different being, and when you are pregnant it increases when they see you physically. Even at other times, all people are eying you. (Interviewee M)

Apart from physical difficulties related to pregnancy the following quotation shows that women worry about anticipated difficulties after pregnancy. Interviewee J explains her worries:

Yes, being pregnant is very difficult for a disabled woman. It is very difficult, not comfortable. I have fallen down three times while I was pregnant; I used to worry, 'Would my child turn out like me ... maybe his hands or legs?' I couldn't sleep at the times I fell down.

Here, the quotation explains that the disability makes the pregnancy time more hazardous. Thus, until the child is born and seen, the disabled woman cannot be certain about having a healthy infant.

Health and reproductive care

Health care and health care education are often not supportive for disabled women. First of all, sexual education often is absent, as the following quotation illustrates:

Once, I was expecting my menstruation to come but it did not come. I expected for a longer period of time and finally I learned that I was pregnant If I knew how to protect myself I would not have got pregnant. But after I knew my condition, I decided to give birth instead of going for abortion. I became a mother without marriage. (Interviewee B)

Teaching disabled women about contraceptives is the responsibility of the professionals in the health centers, as it is not customary to discuss these issues with parents in Ethiopia (Taffa et al. 2017). Generally, in Ethiopia sexual reproductive health is given in schools. But school girls are more influenced by their peers than their teachers (Yesus and Fantahun 2010). Moreover, in Ethiopia not all children go to school, which is especially the case concerning children with disabilities in rural areas (Croft 2013) and thus the regional health center is the best option to reach out for these girls. Yet the majority of the interviewees are not satisfied with the services received from the health centers of Addis Ababa. The following excerpt from an interview with a disabled mother helps to clarify this:

Others can read and understand something about birth control. But it is not for us You must have a third party. It would be good if there were voice equipment or Braille reading in all health centers. Having such aids helps disabled people to get the service without any difficulties. Not only are that, but the roads to the health center other challenges. But it is good to have other aids that assist this group of people. The health

center workers need to have sufficient knowledge about us. In addition to this, there is a need for an information desk that could assist the disabled groups. The disabled group needs to have adequate information like written materials and audio cassettes about birth control, and about health and other health-related issues. (Interviewee B)

This quotation explains the awareness level of medical personnel and the need for special treatment for disabled women. According to the interview result, some doctors are not willing to serve disabled pregnant women properly:

I faced many difficulties from the hospital workers. They were not even willing to give me a medical card. After I learned about their refusal to accept me, I went to the previous hospital and reported everything to the doctor. Then he wrote them a letter and said to me, 'If they refuse to accept you again, call me back and I will take the issue to the court.' Having that letter I went to that medical center for medical treatment, but I did not get that particular person; instead, I got a woman. I informed her of everything that that man did to me, and she gave me a medical card. After that I went to that same doctor who refused to accept me. He did to me the same thing; he did not ask me anything but was asking my assistant about my health condition. (Interviewee A)

Not only it was very difficult for this pregnant woman to get a medical card, she was also ignored as a person because the doctor avoided direct contact with her. All of the interviewees agreed that doctors in Ethiopia are untrained and unaware about disabilities and some training in that sense is needed.

Moreover, as illustrated in the following, doctors may condemn women for being pregnant:

Once I went to hospital for delivery, and there I found a doctor and he took me for delivery. And there I found a doctor and he told me that I made a wrong decision in becoming pregnant. (Interviewee F)

This kind of advice from doctors is the experience of most of the interviewees, and the interviewees suggest that even if the doctors want to give some advice related to the pregnancy, the physicians should not say it during delivery. The other physician was generalizing all disabled women in the country, where there are a limited number of disabled mothers:

When I went to the hospital, as I told you, it was difficult; they do not have much support. They say, 'All these disabled people are in a hurry to give birth. What is it?' ... Yes, they got angry in the hospital. Even when it was said, 'Oh, please let her get in, she's sick' and the like, we were told, 'What is it? Wait' ... The baby was big, as I told you; he was not moving, and it was beyond my capability. When the person who took me to the hospital told the doctor that I was having great difficulty, he said, 'Let her in,' and I got in. I was then examined, and it was said that the labor will be seen after three minutes, but it was not [I then] delivered my baby [by Cesarean]. When a disabled mother goes to the hospital there is no one who quickly takes her to find a solution. (Interviewee H)

As they were not approving the pregnancy of the disabled women, the interviewee had to suffer while waiting until she received proper treatment. Another interviewee finds that the attitudes of people working in the health centers may even lead to medical errors or mischief by doctors:

To be honest with you, I myself used to fear to go to hospital due to the occurrences of medical error. They may be reluctant to help a disabled mother and cause her to die. There are many challenges for disabled people There are times when doctors cut out the womb of a disabled mother without her willingness. (Interviewee I)

This excerpt explains the extent of the physician's egotism – to cut out the womb of the disabled mother – and how the disabled mother was powerless.

Generally, all of the interviewees agree that the awareness level of the medical caregivers and doctors should be changed. Accessibility is also a major difficulty for pregnant disabled women, like the hospital buildings, beds, chairs, and information desks. Foremost, most interviewees were confronted with ignorance or even rejection by the physicians. The battle of the disabled women does not stop here; it continues after they become mothers, although the joy that they get from their motherhood experience reduces their grief

Motherhood

From the interviews, four major sub-themes emerged under motherhood: motherhood feelings, mother–child relationship, motherhood responsibility, and social support and perception. These four sub-themes are presented using the interview results as they were told by the disabled mothers.

Motherhood feelings

All of the interviewees expressed their feelings of motherhood with a good spirit. They consider their motherhood as a source of joy. For example, when Interviewee E was asked about her feeling of motherhood, her eyes became full of tears and she said 'I am very happy that I am a mother. I am very happy that I have a child. I am very happy, thanks to God' Another interviewee articulated her feeling of motherhood as:

It's my children who are responsible for how I go through my day-to-day life. I have these views because they have made it possible for me to love myself, love my life, and become happy. My children are good to me and I can explain their goodness in that they love me. They truly love me a lot, and I can always see this. They understand me. Well, talking about the youngest one understanding physical disability now may not make sense, but my oldest child is now 12 years old. He knows my strength and my weakness. He can understand very well the situation I am in. He knows what physical disability is, and he is proud of me. So I am happy about this; he knows where I need support in the house, and he knows why I need it. He knows how I am different from other people and how I am better than others. This is a big blessing for me; this is a big gift. (Interviewee L)

This excerpt shows that motherhood enabled the disabled woman to love herself and guide her life carefully. The understanding she gets from her children helped her look into herself and find new meanings and directions to her life. She also describes her experiences of motherhood feelings, beyond the caring and loving nature we expect a mother would have for her children. She is able to accept herself and her disability and to love herself through the love and acceptance she gets

from her children. Another interviewee relates motherhood with the feelings of different stages of child development:

Motherhood starts from pregnancy time until your baby grows up. I still remember how I was doing the breastfeeding. It was a very good time. I still remember how my baby used to cry, how he was babbling and crying. All these things have something to do with your motherhood. (Interviewee I)

The motherhood feeling of the interviewees is very positive; while talking about motherhood their faces seem to lighten-up almost as if forgetting the challenges that we were just discussing.

Mother–child relationship

A second theme that emerged from the interviews was the importance of the mother–child relationship. All of the interviewees emphasized having good and harmonious relationships with their children. Interviewee C explained her good relationship against a background of societal expectations on the contrary:

They [society] do not think that with disabled mothers that child–mother relationship exists. They do not think that children are important for disabled women. But for me as I knew that I could be a good mom and knew well my potential, motherhood is something very good and important, and it is a nice experience. We are very close. Based on [my daughter's] understanding level/age level, I always tell her what is good and what is bad. She is very responsive.

As captured in the interviewees, the mother–child relationship often goes beyond mother–child attachment. Interviewee F explained her relationship with her children as follows:

I always talk with my children in a very open manner I always tell them what is good and what is bad. And often I ask them what makes them happy and what makes them feel sorry. Most of the times I ask them to report to me their daily experiences. And they are always reporting what they have faced in their activities. Especially my elder daughter always reports to me anything she encountered in her daily life. We have a very close relationship. She is like both my close friend and my daughter.

In addition to the joy of being a mother, it also shows that the relationship with their children is reciprocal. Women with disabilities have respectful relationships. Their children and husbands challenge the common opinions that stigmatize disability. At the same time, the mother–child relation is different because, due to the dependency of the mother, the mother–child relationship may be more reciprocal than had the mother been able-bodied. Interviewee J presents her relationship with her child as follows:

He is my brother, my son, and 'my everything.' He feels very sorry for me now. He gets up early in the morning, mops the house, prepares the bed, and boils tea. Now I have started learning at night, so he says to me, 'You learn now as you have educated me; I can now tutor you.' He truly does as much as he can; he sets up the things required for the coffee ceremony ... on his own, he prepares wott [Ethiopian traditional sauce] by chopping onions. [A]t this age he [helps] me [by] preparing these, and he consoles me. So I cannot explain the feeling of having a child; it makes you very happy.

The 14-year-old child is the mother's everything, as expressed by the interviewee.

Few interviewees stated that they can handle the motherhood responsibilities by themselves or without any support from others. But from the interview results we could detect that they got help in one way or another. The previous excerpt can be an example of a need for support from their underage children. The following comment also confirms the need for support:

When I was fetching water these days because there was a water cut, he takes it from me and puts it inside the house, saying, 'Stop, you will have pain on your legs,' and thinking about me. He has this understanding. (Interviewee E)

Most interviewees indirectly showed that they get some support from their children, although the intention to have children is not to get support. Thus, we can say that the children of the disabled women support their mothers either willingly or out of consideration for the need for support of their mothers. In Ethiopia, mothers getting support from children is customary but when it comes to disabled women, people relate the support of the children to the disability of the mothers.

Motherhood responsibilities

Most of the interviewees accepted that motherhood responsibility is very difficult unless they get support from another person, especially until the children start walking by themselves:

It is difficult to pick them up and down; I need someone's help. I cannot do it. I cannot move them around. My families help me with this kind of things at home. Otherwise, I cannot do it. (Interviewee D)

This shows that the motherhood responsibility of disabled women requires support from other non-disabled persons. Another interviewee relates the motherhood responsibility with the perception of society as follows:

When my children get sick, even if my sister who is with me or the father of my children are there, if I don't face a problem which I cannot get out of I always go [to the doctor with them] [...] people felt that my presence there was unnecessary and they made comments. What these show me is that when people see this they just think that physically disabled women are unable to give birth to a child. If they think that it's possible they would ask whose child he is. My children are always thought to be my sister's children. It doesn't stop there; they say, 'Why is it necessary for her to come?' Even when you tell them that they are my children, they ask, 'Then why did she come?' Physical disability doesn't stop a mother from giving her child the necessary things. At least there is the psychological want to be with your child when he is sick, not to be apart, to take care of him yourself, you yourself wanting to hear what the doctor says and explaining the conditions that were there. (Interviewee L)

From this excerpt we can see society's denial of the opportunity to look after the health of a child. When it comes to the disabled mother's experience, society denies her existence around the sick child. The excerpt also shows how society ignores the psychological needs of the disabled mother.

Social support and perception

Although women face societal condemnation for becoming mothers, at the same time these children are seen as a resource for the disabled mothers. Indeed, as we have already shown, children are important for providing practical and emotional support. Yet again, the interviewees indicate that they often face derogatory remarks suggesting that the support is the reason to have children. In Interviewee A's words: 'Society is happy when we give birth but they say, "She gave birth to guide her or help her." They do not focus on our motherhood.' Interviewee B reveals the same idea in a different way:

For example, nobody says 'your child' but they say 'your eyes' or 'your guide.' I did not give birth to my child to show me a way; I gave birth to my child because I had to. For example, I do not take my daughter to place she does not want to go. She can join me only if she wants to go with me. I am not forcing her to lead me the way; it is not my intention. But people attached it with the idea of guiding me.

Another interviewee emphasized the same idea by saying:

But when your family members such as your aunts, brother, sister ... have negative attitudes towards you, it can affect your emotions. They cannot see my motherhood as they see the motherhood of others. They think as if I get someone who can assist my blindness. They do not think that I need a child like other mothers do. (Interviewee C)

As mentioned by the interviewees, society does not think that disabled women can care, love, and do other things that mothers do for their children. The interviewees noted that there are groups of society who consider the motherhood of disabled women as creating problems for both the mothers and their children. According to Interviewee I, there are also people who tell the disabled women that they do not have to give birth:

I remember on the fourth day after I gave birth I had to go to the hospital I was not able to climb into the car, and the driver was worried a lot. Finally, they put some stone so that I could climb up in the car. I remember he said to me, 'You don't have to try to give birth again; you should stop it here.' ... People who are very close to me used to tell me that they may not take such responsibility if they were me. They say that they may adopt their nephew. We have many sacrifices that we are making as mothers. But it gets doubled when it comes to disabled mothers.

This excerpt demonstrates a person's determination to advise the disabled mother not to have more children due to the challenge he observed. The same interviewee indicated two attitudes of society toward motherhood:

There are two types of people: The first group is those who disregard your motherhood, and the other group is those who appreciate your motherhood. There are times when your kids are considered as someone else's kids because people don't believe that you are capable of motherhood. At the same time there are groups who appreciate your motherhood, as they see the sacrifice you are making to raise your kids as the other mothers do If there is some stumbling block around me, I will take it out from my way and keep going You have to pay every necessary price for what you brought to this earth. (Interviewee I)

This quotation shows the determination that the interviewee has to fulfill her motherhood responsibilities regardless of the good and bad influences of society. The perception of society is further discussed as follows:

She is a very well-known person. She is an artist, and we got along well since we had the media in common. She said, 'Congratulations on your new baby; what did you have?' I said I had a baby boy. She asked, 'Is the child also like you?' They think that if you are a physically disabled person, the child being born will also be a disabled one. When you get married also they think that your partner is also a physically disabled person. They ask, 'Is your husband also like you?' I thought how they see it. We are in a community that concludes that a visually impaired person will have a visually impaired kid. Living in this community is difficult. I do not say it is easy. The main thing is the strength of the physically disabled mother. Otherwise, it is not easy. It depends on the way you respond to it. (Interviewee K)

This quotation explains the awareness level of society about physical disability, motherhood by disabled women, and their relationships. Another interviewee mentioned the family disobeying the motherhood rights of disabled mothers:

But while the birth mother is there, the child may be told that her sister who didn't give birth to him is his mother, and he might not have the correct name of his father. Parents may do this because of not accepting the physical disability, and they might think that they are protecting the child and taking care of the child by doing so. But this deprives the mother of the grace of motherhood – her right. And the child may know about it later on, and when he does it is going to be something which will hurt him Even if she is a physically disabled mother in a difficult situation, she should be helped so that she can enjoy her motherhood experience. And the children should also know about it and live in this condition so that it is not difficult for them. (Interviewee L)

This excerpt shows the scope of family interference to the extent of refusing to acknowledge the disabled woman as the child's mother and telling the child that some relative is his or her mother. This type of social influence excludes the disabled mother from the grace of motherhood (as stated by the interviewee) and also creates a negative effect on the child when he or she identifies the real mother with a disability.

In sum, motherhood experiences for the disabled women in general were gratifying for the women. It enabled to give and receive love, trust, and respect and also responsibilities and social support. Motherhood for all of the respondents, despite adding challenges to their daily life, has empowered the women and given them grace.

Discussion

This article focused on the life experiences of disabled mothers in Ethiopia. The major themes selected were the challenges of the disabled women in intimacy and their married lives, their pregnancy and childbirth, and their motherhood experiences. Interviews were held with 13 employed disabled mothers from Addis Ababa, the capital city of Ethiopia.

Most of the interviewed mothers with disabilities reported that society doubts their ability to be intimate, to become a wife and mother. Here we reflect on our empirical data with three complementary but not mutually exclusive theoretical frameworks: the capability approach (Sen 1993), the (family) quality of life approach (Hoffman et al. 2006), and the disability culture perspective (Peters 2000).

We found it significant to discuss the personal accounts of the interviewed women in a wider conceptual perspective. Moreover, reflecting on our material from the capability approach, the (family) quality of life approach, and the disability culture perspectives gives practical potential and thus may offer opportunities to improve the lives of mothers with disabilities.

Capability approach

The capability approach is an ethical framework which states that social justice should focus on supporting the capabilities of individuals to conceive, pursue, and revise their life plans (Sen 1999; Alkire 2002, 2005; Robeyns 2005; Nussbaum 2006; Vizard 2006). The capability approach was developed by Sen (1980, 1993, 2009) with two questions as a starting point. One question is on the individual level: what is really important in people's lives for their welfare and well-being? The other question is on the societal level: suppose we want to determine how well a community manages to create a just society, how would we measure that? In the light of the first question, the capability approach stresses the importance of values that people should achieve with and in their lives. Sen speaks of 'beings and doings people have reason to value' (Sen 1993, 31). In the light of the second question, people should be enabled and facilitated to realize these 'beings and doings'. This means that people should have the freedom to have the identities they choose (beings) and to do the things that add value for themselves and their environment (doings). Capabilities stand for a person's opportunity and ability to realize valuable outcomes, taking into account relevant personal characteristics and external factors: being able and enabled. In the capability approach it is recognized that all people are different in their resources and characteristics. Because people differ in their 'inputs', people also need different means or 'conversion factors' to achieve equity in opportunities and outcomes. So justice in the capability approach is not considered as equality in means (everybody has the right of the same means) but as equity in outcomes (everybody should have the same opportunities to achieve valuable outcomes). Nevertheless, our data imply that the women with disabilities do not have equal opportunities.

According to Sen, important values are group and context dependent and should not be formulated by experts but 'collected' in the target group in a democratic procedure. Values are 'transformed' to capabilities if they are important for a person in his/her life situation and if she/he is enabled and able to achieve the value in their live. Thus, the context is essential as our results show they mainly obtain what they do not value.

If we apply this framework to our empirical material we can consider the three emerging themes – intimacy, pregnancy, and motherhood – as capabilities: they are valued highly by the target group of disabled women. However, on the cultural and societal levels these values of intimacy, pregnancy, and motherhood are almost denied on the identity level to women with a disability. Obviously, for society the women in our interviews are ‘reduced’ to the single identity of being disabled, which leaves no room for and is not compatible with the identities of being an intimate partner, being pregnant, or being a mother. Partly as a consequence of this and partly as an independent factor, ‘doings’ are also difficult to achieve. Achieving appropriate medical care, for instance, is problematic because of the attitude of professionals (consequential to the identity issue), but also because of accessibility.

Notwithstanding these negative societal ‘conversion factors’, the women in the interviews show an admirable strength to overcome this opposition. They have already faced resistance in their lifespan and found ways through them. It can be argued that mothers with disabilities bring more personal resources and conversion factors to creating motherhood on their own terms than non-disabled women. They can do it again. They have already learned to survive with limited information and resources and they can use those skills for this new challenge.

Moreover, the study implies the need for entitlements from society that women with disabilities have to achieve equity; that is, the need to have more means to compensate for their disability. This is important as our results show they receive less means in practice.

Family quality of life approach

The findings of this study indicate interconnectedness between several life domains including family and social interactions, and emotional, physical, and material well-being. These life domains are conceptualized in (family) quality of life constructs that reflect a sensitizing approach to various challenges and provide a framework for understanding disability (Brown and Faragher 2014). Quality of life can be reflected as a model that recognizes what is important, necessary, and satisfying in human way of life. Quality of life can be understood as achieving goals in major life settings at a personal level and social well-being enjoyed by families and the wider community (Schippers and van Heumen 2014). With the recognition of the family as an important resource for persons with disabilities, but at the same time the impact disability has on family life, family quality of life domains were formulated, including family interactions, parenting, emotional well-being, physical and material well-being, influence of values, and disability-related support (Samuel et al. 2012).

Overall, we can conclude from the findings in the Ethiopian context that the family quality of life domains that are related to the three themes of this study – parenthood and disability-related support – have impact on the majority of

the interviewed disabled women. This is mainly due to the socially constructed beliefs – the domain of influence of values – that disabled women do not fulfill the requirements of being wives and mothers. On the one hand, the interview results showed that disabled women believe that being intimate, pregnant, and mothers contributes to their quality of life. On the other, the influence of culture and beliefs of society keep disabled women in their disadvantaged position.

The influence of values is eminent in this study. In Ethiopia, married life is perceived as the ultimate purpose in life for women. It is believed that satisfaction in married life will improve all other quality of life domains. Society will pity a woman if she is not married and does not have children. Moreover, although Ethiopian culture expects women to get married before giving birth, society has always disapproved disabled women marrying and having children. This is because in Ethiopia women are heavily involved in domestic labor although this is mostly unrecognized and undervalued. Despite this fact, domestic labor is recognized as substantial and important for the sustaining of the families and disabled women are not seen as capable of performing these tasks.

Thus, society is marginalizing disabled women by using negative attitudes and assuming an inadequacy of providing care and well-being for their children and/or family. Therefore, it is not surprising that being married to and parented by women with disabilities are often seen as negative experiences instead of positive events. Despite the growing number of women in our society who have a disability, this attitude still exists in developing countries such as Ethiopia. This indicates, in the context of Ethiopian culture, that disabled women themselves, but also their families and the wider community in general, will perceive their quality of life as low.

Furthermore, for most interviewed mothers with disabilities, their decision and ability to engage in marriage and parenthood were not without challenges of their own. They face resistance not only on being intimate, but also after getting married and becoming pregnant. For instance, as expressed by most of the interviewees, in the medical centers there are no disability-related supports, which is another major family quality of life domain: accessible, affordable, and appropriate health care.

Despite the absence of an infrastructure that supports physical and material well-being, and societal values that negatively influence the (family) quality of life, the resilience that disabled women have shown through their ability to give and receive loving relations with their children and their ability to raise children in relatively good health has empowered them to such an extent that they experience a much better quality of life since becoming mothers.

Disability culture perspective

Progressively, academics from the disability community call for using a disability culture perspective (Kirsbaum 2000; Peters 2000; Kupperts 2011; Ripat and Woodgate 2011); that is, recognizing disability as a socially constructed concept and pinpointing variables that encourage flexibility. This view shifts the emphasis

from impairment to the stigma, prejudice, discrimination, marginalization, and disempowerment imposed on women with disabilities (Green et al. 2005; Van Brakel et al. 2012). In the Ethiopian context, the voice of people with disabilities is recently becoming much stronger, as is reflected in several grass-roots and self-advocacy movements. For example, the Ethiopian Women with Disabilities National Association is a non-profit organization based in Addis Ababa, founded in 2002 by seven women with disabilities and one professional volunteer. Our study can accelerate movements like these by showing that the disability experience brings a unique expertise to motherhood issues. Despite growing determinations to admit and support cultural experiences within most social structures, there is little awareness about disability culture among a wide array of society. This study reveals that disability and motherhood experiences contest customary stereotypes of incapable and helpless individuals, normalize the experience of having a disability, encourage independent functioning, and provide positive role models and disability-appropriate solutions. These cultural perspectives are especially important when considering mothers with disabilities who are exposed to general societal stigma and unjustified assumptions over their parenting capabilities. Finally, our data suggest that offering resources may facilitate women with disabilities in more fully enjoying intimacy, marriage, and motherhood. Policies regarding family and social supports, such as accessibility, adapted services and communication, home modification, and community access, can strongly move the common family functioning and public involvement of mothers with disabilities and their families (Hu et al. 2011).

Strengths and limitations of the study

This study is to our knowledge the first study on this topic of Ethiopian disabled women. Actually, choosing interviewees only from Addis Ababa limits the discussion in these regards. However, it is generally very difficult to get access to disabled women in the rural parts of Ethiopia, for instance because parents hide their disabled daughters fearing the prejudice of society. Nonetheless, selecting interviewees who are employed and live in the city, Addis Ababa, showed the difficulty for the employed disabled women of the city in realizing their motherhood. Moreover, from the challenges and difficulties experienced by relatively successful employed disabled women, we can only infer the immense extent of challenges and difficulties disabled women and/or mothers in rural parts of Ethiopia might face. The women in rural areas lack the independence of having (at least some) salary to support themselves with their child(ren). Furthermore, society in Addis Ababa is relatively more aware about disability issues compared to those who reside in the rural part of Ethiopia. Infrastructures such as roads, houses, schools, and hospitals are much better in Addis Ababa even though they are still extremely insufficient.

Another limitation of the study is that we asked the interviewees about their experiences as a 'disabled' mother. Adding the adjective 'disabled' may have elicited defensive reactions from the interviewees. Women were reluctant, for instance, to come up with possible negative effects of difficulties their children encountered. They emphasized their children's strength, happiness, and opportunities as a consequence of having a disabled mother. Because this experience may certainly be one side of the coin, asking more openly about their experience as mothers may have also revealed possible difficulties.

Practical implications and conclusion

Our study contributes to understanding the grace of motherhood of disabled women of the world. First and foremost, our interviewees find agency, resilience, and pride in their experiences of intimacy, pregnancy, and motherhood. This enables them to face physical and material challenges, negative societal expectations, and hardships. By sharing their experiences, women can empower and help each other. Also, transferring the communal family functioning and public participation in the lives of mothers with disabilities and their families requires policies regarding family and social support. Adapting policies regarding individual, family, and social supports, such as accessibility, adapted services and communication, home modification, and community access, is highly needed in the Ethiopian context. In turn, they can positively impact the common functioning and public involvement of mothers with disabilities and their families.

Furthermore, our findings may help in communicating to the larger society to enhance the awareness people have about the love and competence disabled women have in intimacy and motherhood.

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